

# VISIONS & VALUES

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## ACTION PACKED LEGISLATIVE SESSION

From start to finish, the 2005 Legislative Session was a busy one. In January, the legislature was asked to ratify the changes to the rules for the Children's Special Health Program that had been implemented effective October 1. Advocates and parents spoke out in committee about the harmful effects of these changes. After considerable scrutiny, the House reluctantly approved the changes but directed the agency to pursue both short and long-term solutions to the effects of these changes.

Concern for children with disabilities also caused the Council and other advocates to oppose legisla-

tion which would have allowed a student to be charged with a misdemeanor for disrupting the educational process, loitering on school grounds/facilities, or whose presence was found to be detrimental to the morals, health, safety, academic learning or discipline of the other pupils. The Council, Co-Ad and others provided alternative language that would have protected special education students but no consensus could be reached. The bill died in the Senate.

Legislation that would allow ADA public accommodation complaints to be heard at the state level was passed with overwhelming support.

(continued on page 8)

## The Meaning of Self Advocacy

by James Steed

What does it mean to be a self advocate? To me a self-advocate means someone who speaks up for themselves. A self-advocate decides what happens in their lives. Self-advocates take responsibility for their actions and decisions. A self-advocate grows and learns from their mistakes and does not use their disability as an excuse, *"I am not responsible because of my disability."*

A self-advocate may be defined as "having the freedom to make choices to live life to its full potential. In other words, **self-advocates:**

1. Make choices in their own lives.
2. Have control over the supports that will bring them independence and control over their own lives.
3. Practice the philosophy of "nothing about me without me."
4. Take risks.
5. Take responsibility for their mistakes

When a person with a developmental disability decides to become a self-advocate they may encounter barriers. These barriers may be

(continued on page 4)



## COUNCIL PROJECTS

**Be DETERMINED****Rally! ... for Self-Determination!**

Council staff and regional and community teams are busy making plans for the statewide bus tour that will promote awareness of self-determination for adults with developmental disabilities. The tour begins Thursday, June 16, in Preston in southern Idaho and one day later at Bonners Ferry in northern Idaho. Both tours will arrive in Boise, June 23, for the following day's grand finale at 2:30 in front of the Idaho Capitol.

When the two buses arrive in Boise, they will have traveled a combined 1600 miles and will have conducted self-determination rallies in 35 cities and towns throughout the state. Community organizers far from Boise are delighted to have a rally in their town. Organizer

Annette Nash in Preston said, "I really like having a rally here because it's something I won't have to go to Boise to experience."

One of the most energetic organizers has been Lorraine Crocket in St. Anthony. She has invited the mayor and city council, is scheduled to give a television interview, and is getting lots of support from local citizens and businesses. In northern Idaho, Jill Smith, Trish Miles and Chelsea Dennis have formed an effective working partnership while planning rallies for Sandpoint, Post Falls and Coeur d'Alene.

Information about the tour and rallies will be sent shortly. For more information, contact the Council Office.

**Home Of Your Own (HOYO) Has New Home**

Opening Doors, Inc., will soon begin helping people with developmental disabilities to realize their dreams of becoming homeowners. As a non-profit business, Opening Doors will receive grant funding to assist people with making a down payment and help them qualify for low-interest housing loans. Banks, real estate agencies, mortgage loan companies, other businesses and individuals are contributing funds for operating capital.

Idaho Housing and Finance Association provided start-up funding for Opening Doors because it met the qualifications for being a Community Housing Development Organization (CHDO). As a CHDO, Opening Doors' primary mission is to develop housing for people with disabilities.

The 2005 goal for home loan closures is 6, and the 2006 goal is 13 home loan closures. Only qualified people and families residing in the 10 county area of Health & Welfare Regions 3 and 4, exclusive of the city of Boise, are eligible at this time.

To learn more contact Opening Doors at (208) 371-6849.

**A New Partnership**

The Idaho Council on Developmental Disabilities has formed a new partnership with the University of Idaho Center on Disabilities and Human Development to co-sponsor the Idaho Partners in Policymaking program. As in the past, funds are also being provided by the H&W Developmental Disabilities Program and the State Department of Education. Trina Balanoff, a parent and 2003 graduate, is the new statewide coordinator for the program.

The 7<sup>th</sup> class of Partners began on April 8, 2005. Partners

in Policymaking is a leadership development training designed for adults with disabilities and parents of children with disabilities. This year's class has 22 participants who represent a variety of disabilities across the 7 regions of Idaho. "Thank you for helping me understand that I need to teach my children to advocate for themselves", says Dani St. Onge of Coeur d'Alene.

For more information about Partners please call Trina Balanoff at (208) 841-9293 or visit the program website at <http://idahopartners.state.id.us>.



## COUNCIL PROJECTS

### Council Five Year Plan To Be Developed

Council staff will soon be gathering information to develop the Council's Five Year Plan for fiscal years 2007 – 2011. Idahoans will be asked to identify areas where the Council could create new opportunities or, make positive changes to existing problem areas being experienced by people with developmental disabilities, and/or their family members.

Surveys and focus groups will be the primary means for gathering input, not only from people with developmental disabilities and family members, but from public and private agencies and businesses. Suggestions and issues will be presented to the Council and a draft plan will be developed. The draft plan will be made available for public comment and those comments will be reviewed and considered for inclusion in the plan by the Council. The resulting plan, as approved by the Council, will be submitted to the Administration on Developmental Disabilities by August 15, 2006.

#### COUNCIL VISION:

*"All Idahoans participate as equal members of society, empowered to reach their full potential as responsible and contributing citizens of their communities."*

### SALN Continues to Expand

The Idaho Self-Advocate Leadership Network (SALN) has three new teams to add to the statewide network. Regions 2 (Moscow-Riggins area), 5 (Hailey-Twin Falls-Rupert area), and 6 (Blackfoot-Preston area) will complete their leadership training the first weekend in June.

The five teams are available to train people with disabilities, parents, service providers, and state agencies about self-advocacy and self-determination

in these areas and in Region 1 (Bonners Ferry- St. Maries area), and Region 7 (Salmon-Idaho Falls area).

Congratulations to the following members for completing the self-advocate leadership development training: **Bob Quast** from Region 1; **Thomas McKnight** and **John Russell** from Region 2; **David Dekker**, **Lia Haile**, and **Bridget Shanahan** from Region 5;

**Larry Fries**, **Tracy Martin**, and **James Steed** from Region 6!

This fall, the Council will be recruiting self-advocates from Regions 3 and 4 (southwest Idaho) for SALN teams. Please contact Christine Pisani at the Council office if you are interested.



*David Dekker, Lia Haile and Bridget Shanahan, Region 5 SALN*

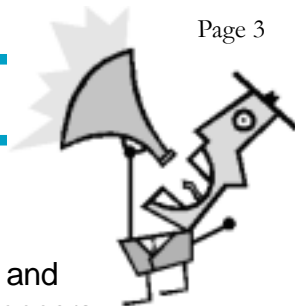
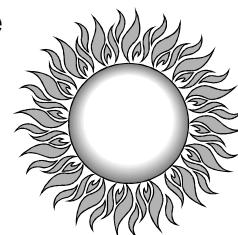
### Youth Leadership Summit

The Council is once again collaborating with the Idaho Bureau of Special Education to provide youth leadership development opportunities in Idaho. This summer, instead of the traditional week-long Youth Leadership Forum, a Youth Leadership Summit is planned for August 2-4 in Boise.

Many YLF alumni from the past four years will be invited in addition to other stakeholders including Idaho Self Advocate Leadership Network members,

teachers, employment representatives, parents, and advocates representing independent living and disability issues.

The goal is to develop a plan for future youth leadership activities in Idaho with the majority of planning participation and input being driven by youth with disabilities. For more information please contact Tracy Warren at the Council office.



## STATE NEWS

### KIP Groups Begin in Pocatello

James Steed, member of The Idaho Self-Advocate Leadership Network has started what he has named "KIP." KIP stands for **Knowledge is Power**. The KIP group is for people with disabilities, their families, and friends. The purpose of KIP is to provide information about best practice in the field of disability, and host speakers from agencies and organizations that assist people with disabilities. The meetings are about an hour and are free to all who attend. The Pocatello Independent Living Center, LIFE, Inc. will host the monthly KIP Groups. "The reason I wanted to start this group is

because I felt the more people know, the better self-advocates they can become. In May the "KIP Group" hosted Idaho State University's Todd DeVries, Coordinator for the Center for Students with Disabilities. He spoke about services available on campus for all students with disabilities attending Idaho State University. Topics have been planned through October and include Pocatello Regional Transit, Vocational Rehabilitation, The Idaho Self-Advocate Leadership Network, Pocatello Housing Authority, and Adaptive First Aid. To find out more about KIP, contact James Steed at LIFE, Inc. at 208-232-2727.

#### Self Advocacy *(cont. from page 1)*

people in their lives who will try to make the decisions for the self-advocate. These same people may say a self-advocate can't do something because they are person with a developmental disability. Be strong. **Use your voice** for the choices you want to make for **your life**. Surround yourself with people who believe in you and will help you get what you want in your life. Remember, things about your life should not be planned, discussed, decided, or written down without you making the decision and being involved the discussions. Simply put, **"nothing about me without me!"**

### CPI Conference 2005

#### Opening Doors: An Invitation to Learn and Celebrate Together

Community Partnerships of Idaho invites you to attend their 9<sup>th</sup> annual training conference scheduled for October 27, 28 and 29<sup>th</sup> at the Boise Doubletree Riverside Hotel. This conference is for self advocates, parents and professionals and is co-sponsored by a number of state and local agencies, including the Council on Developmental Disabilities.

Conference tracks will focus on Self Advocacy, Disability Awareness, Employment Services, Mental Health, Developmental Disability-Adult, Developmental Disability-Children,

Supervision/Leadership and Personal/Professional Growth. The "Self-Advocacy" track was first offered in 2004 to provide an opportunity for people to learn how to become self advocates and the reasons why it is so important to speak out.

This year the conference will feature nationally renowned keynote speakers: Richard Pimental is a leading expert in the nation on Disability Management, Job Recruitment, Job Retention, Americans with Disabilities Act and Attitude Change; Lynn Seagle is one of the country's leading consult-

ants in Organizational Development and Supported Living Services.

For 2005 there is a new track on Early Childhood Services which will provide information on ways to make a classroom inclusive. These sessions will be great for teachers, childcare providers, church school teachers, parents, and administrators.

For more information go to [www.openingdoorsconference.com](http://www.openingdoorsconference.com) or [www.cp-of-idaho.com](http://www.cp-of-idaho.com) and click on the conference link or call Patricia Scott at (208) 376-4999 xt. 225.



## STATE NEWS

## CSHP Summit

The Idaho Division of Health, in collaboration with several advocacy groups, is planning a summit of key stakeholders to discuss the recent reduction of the Childrens Special Health Program services. The goal for the group is to develop long-term, sustainable solutions for Idaho to ensure that children with special health care needs continue to receive the services they need. The first meeting is to be held in June, date TBD.

## DDA Rules Revision Process Nearing End

The public will soon have an opportunity to review and make comment to a revised set of Developmental Disabilities Agencies rules. Work by the negotiated rule-making group will end in June and the proposed new set of rules will be open to public review soon afterward. Copies of the proposed rules will not be available until August when they will be published in the Administrative Bulletin and reviewed in public hearings. Those hearings will most likely take place in Coeur d'Alene, Boise and Pocatello or Idaho Falls. Exact location and hearing dates and times have not yet been established.

The Council will continue to participate in the negotiated rule making group and track the progress of the public participation process. We will announce information via e-mail and other means as it is made available.

## Medicaid Option for Self-Directed Services Moves Forward

Collaborative work between Medicaid and stakeholders continues on finalizing the development of implementation strategies to allow Idahoans with developmental disabilities to have more control over the services and supports they need. Groups are meeting to complete a support broker training model,

fiscal management service requirements and quality assurance guidelines for the entire process.

A concept paper on the proposed self-directed services option has been submitted to CMS for review with plans for submitting a waiver amendment soon.

### Self Direction FAQs (first in a series of articles)

**What is a self-determination waiver?** President Bush directed the federal Medicaid agency (CMS) to develop and promote Medicaid waivers that will promote greater flexibility, control, and access to community resources for people with disabilities.

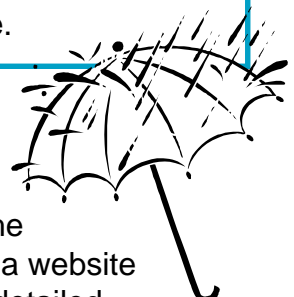
**How is it different from what we already have?** Current waivers have a limited list of services that can only be provided by certified providers according to a set of regulations and at predetermined rates of reimbursement. In self-direction, the individual decides what types of supports they need and can purchase them from whomever can do the best job, at a negotiated rate.

## Connecting Families

The Idaho Family Support Project successfully applied for and received a federal Family Support 360 grant to expand and enhance family support activities in Idaho. One component of the grant is to create a system of one-stop information centers in the state to help families locate the information they need in their geographic area. Currently there is a resource center that has been successfully up and running in Lewiston that serves Clearwater, Idaho, Latah, Lewis, and Nez Perce counties.

Another component of the grant is to build a website that includes a detailed catalog for families and professionals to access the information they need.

The information and links have been chosen to help families throughout their lifespan and designed with region-specific resource listings. Although still under construction, you can check out this wonderful website at: **[connectingfamilies.net](http://connectingfamilies.net)**



## NATIONAL NEWS

### IDEA Reauthorized with Changes

Last December, the Individuals with Disabilities Education Improvement Act, P.L. 108-446, was passed which reauthorized IDEA with some key changes made:

IEP's no longer must include benchmarks or short term objectives for some children.

Members of the IEP team may be excused from being in the meeting if their area is not being discussed and their input is given in writing before hand.

Changes were made in the area of discipline related to placing a child in an alternative educational setting and deciding how, or if, the behavior is related to the child's disability. With

change in placement decisions, 45 days now means 45 school days (not calendar days) - a much longer period of time.

Additions to IDEA to align it with the No Child Left Behind Act (NCLB) included requirements for "highly qualified" teachers and "early intervening services" for students who have been determined to need help academically, but are not necessarily eligible for special education services.

A complete summary of changes to the law can be found on the IDEA Partnership website at: [www.ideapartnership.org/whatsnew.cfm](http://www.ideapartnership.org/whatsnew.cfm).

### Reauthorization of the DD Act

2006 will bring with it the reauthorization of the federal law that authorizes DD Councils and their sister agencies, the University Centers for Excellence in Disabilities, Education and Research, and the Protection and Advocacy organizations. Although the law has been amended several times, this is only the 3<sup>rd</sup> reauthorization since Councils were created over 30 years ago.

A Task Force of the National Association of Councils on Developmental Disabilities is currently gathering comments from Councils about what elements of the current law they think should be maintained and what ones need updating or restructuring. Some of the language is ambiguous or misleading when compared to what Councils are charged to do: advocate, change systems, and build capacity of services and supports for individuals with developmental disabilities. Once this information is gathered and discussed, NACDD will engage in further dialogue with sister agencies and the Administration on Developmental Disabilities to make recommendations for a draft bill that we can all support as it moves through Congress next year. Council Chair, Theresa Wilding, serves on this Task Force.

### Social Security Changes

Recently, the House Ways and Means Committee announced it will hold weekly hearings on proposals to change Social Security starting on May 12, with hopes for a draft bill by early June. In a recent troubling development, the Committee Chairman, William M. Thomas (R-CA) stated that Congress should consider splitting off the disability and survivors programs. Thomas, who was the driving force behind the passage of the \$1.8 trillion in tax cuts and a Medicare prescription drug bill during the first Bush term, proposes to separate retirement, disability and survivor's programs into "three pots." Married workers do better than

single workers under the current system, Thomas said, because Social Security provides benefits to widows and orphans. "If you take survivors and dependents and take them out of the structure right now you can actually create a true insurance program for beneficiaries and you can create a true insurance program for those on disability," he said. Marty Ford, vice chairwoman of the Consortium for Citizens with Disabilities, said Thomas's idea concerned her. "It sounds to me like it would be a fundamental change to the program," which "although it needs changes, basically it works." The Senate Finance Cmte. began its Social Security hearings on April 26, 2005.

## EDITORIALS



Theresa Wilding,  
Chairperson

### The Bridge Builder

Bridges, no matter how large or small, make traveling easier. Whether it is the magnificent Golden Gate Bridge or the small wooden bridge over our local canal, they allow us to get to

where we are going easier. Some bridges may take us a lot of time, effort, and hard work to build, but after completion, they are well worth the time and serve not only ourselves but also many people who will have to travel the same road. As we work to build bridges in Idaho for people with disabilities, sometimes the work is difficult and requires much time, but each one can make the journey easier not only for ourselves but others who follow behind.

An old man, going a lone highway,  
Came at the evening, cold and gray,  
To a chasm, vast and deep and wide,  
Through which was flowing a sullen tide.  
The old man crossed in the twilight dim;  
The sullen stream had no fears for him;  
But he turned when safe on the other side  
And built a bridge to span the tide.

"Old man," said a fellow pilgrim near,  
"You are wasting strength with building here;  
Your journey will end with the ending day;  
You never again must pass this way;  
You have crossed the chasm, deep and wide—  
Why build you the bridge at the eventide?"

The builder lifted his old gray head:  
"Good friend, in the path I have come," he said,  
"There followeth after me today  
A youth whose feet must pass this way.  
This chasm that has been naught to me  
To that fair-haired youth may a pitfall be.  
He, too, must cross in the twilight dim;  
Good friend, I am building the bridge for him."

~Will Allen Dromgoole



Marilyn Sword,  
Executive Director

### A Lesson For Us All

As I started to write an editorial for this issue of *Visions and Values*, I could not help but

keep coming back to the one subject that has captured the attention of everyone across the country – that of the life and death of Terri Schiavo. Without question, this tragic situation has columnists editorializing, people writing (or re-writing) their wills, and families and co-workers engaging in often heated debate.

If the lessons learned by the life of Terri Schiavo are to have any lasting meaning it is this –

each person has the right to determine how they want to live their life. This requires everyone to think carefully about their own personal life – and death – choices and then make an informed decision that reflects their preferences and put that decision in writing. The Schiavo case reminds us that it is never too early to do this. Life can change in an instant and then, so will that choice. Without written documentation about a person's preference, the decisions will be left, as they were in this case, to family members, or even to complete strangers. And as we know, the family

members may disagree or be influenced by circumstances that having nothing to do with what the person would have wanted.

In Terri Schiavo's case, the family conflict resulted in the courts and national politicians involving themselves in this most personal decision. None of these people knew Terri. They injected their own personal values into this situation or made rulings based on legal precedent. Even the medical community was divided over what should be done. But this was one woman's life and now it is gone. None of us will ever know if that was what she would have wanted.

## Legislative Session

(continued from page 1)

The Human Rights Commission will take on this responsibility and give both individuals with disabilities and businesses access to local dispute resolution on these matters. The State Independent Living Council and the ADA Task Force spearheaded this effort.

Medicaid Buy-In once again raised its head and once again was not approved or funded. The bill did pass the Senate

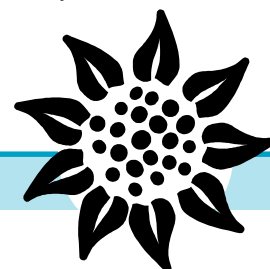
under the very able co-sponsorship of Senators Dick Compton and Shawn Keough but was held in the House.

HCR 12, which authorized continued work on Idaho's self-determination waiver for people with developmental disabilities, passed both houses smoothly. The Council worked closely with the Division of Medicaid on this resolution and provided testimony in support.

And last, but certainly not least, the Council made its first

presentation to the Joint Finance and Appropriations Committee (JFAC). This gave the funding committee the opportunity to learn more about the Council. The legislature did not approve a funding increase but did restore a staff position that had been cut four years ago.

All in all, the session was a productive and positive one.



### WHAT'S HAPPENING

#### JUNE

- 10-11 Partners in Policymaking
- 15-24 Be Determined Bus Tour
- 24 Interagency Council on Secondary Transition

#### JULY

- 8-9 Partners in Policymaking
- 13-15 Self-Advocate Leadership Network Summit
- 22 State Independent Living Council meeting
- 27-29 Idaho Council on Developmental Disabilities meeting

#### AUGUST

- 2-4 Idaho Youth Leadership Summit
- 12-13 Partners in Policymaking
- 19 Interagency Council on Secondary Transition

#### SEPTEMBER

- 9-10 Partners in Policymaking
- 16 Infant Toddler Coordinating Council

#### OCTOBER

- 6-7 Council for Exceptional Children, Sun Valley
- 27-28 Community Partnerships of Idaho Conference

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